



Lupus and Women

What Is Lupus?

Lupus is an autoimmune disease in which the body literally attacks itself, harming its own healthy cells and tissues. It can affect the joints, skin, kidneys, heart, lungs, blood vessels, and brain, causing inflammation and damage to tissues. For most people, lupus is a mild disease affecting only a few organs. For others, it can be disabling and cause serious and even life-threatening problems. One in five people with the disease are disabled, most commonly from fatigue and joint and muscle pain. Fifteen to 20 percent of all cases of lupus result in death, most commonly from kidney disease, infection, and cardiovascular disease. Currently, there is no cure for lupus. However, with early diagnosis and appropriate treatment, symptoms can usually be managed, and most people with the disease can lead active, healthy lives.

Who Has Lupus?

Lupus affects 1.4 million people in the United States (1 in 85). Ninety percent of lupus patients are women, striking most often between the ages of 15 and 44. Lupus is three times more common in black women than in white women and is also more common in women of Hispanic, Asian, and Native American descent. Researchers are trying to learn why these women are more susceptible.

What Are the Different Types of Lupus?

Systemic lupus erythematosus (SLE) is the form of the disease that most people are referring to when they say "lupus". SLE can affect many parts of the body and its symptoms can range from mild to serious. Although SLE usually develops in people between the ages of 15 and 45 years, it can occur in childhood or later in life as well.

Discoid lupus erythematosus (DLE) mainly affects the skin, causing a red, raised rash on the face, scalp, or other parts of the body. The rash may become thick and scaly and may last for days or years. A small percentage of people with DLE later develop SLE.

Drug-induced lupus is a rare adverse reaction to certain medications. Its symptoms are similar to those of SLE (arthritis, rash, fever, and chest pain, but not kidney disease) but they go away when the drug is stopped. Common medications that may cause drug-induced lupus include hydralazine (Apresoline_), procainamide (Procan_, Pronestyle_), methyldopa (Aldornet_), quinidine (Quinaglute_), isoniazid (INH_), and some anti-seizure medications such as phenytoin (Dilantin_) or carbamazepine (Tegretol_). However, not everyone who takes these drugs will develop drug-induced lupus. Only about 4 percent of the people who take these drugs will develop the antibodies suggestive of lupus. Of those 4 percent, only an extremely small number will develop drug-induced lupus.

Neonatal lupus can affect some newborn babies of women with SLE or certain other immune system disorders. Babies with neonatal lupus may have a serious heart defect. Other affected babies may have a skin rash, liver abnormalities, or low blood counts. Neonatal lupus is very rare, and most infants of mothers with SLE are entirely healthy.



What Causes Lupus?

Although the cause of lupus is unknown, it is likely a combination of genetic, environmental, and possibly hormonal factors. The exact cause may differ from one person to another. Research suggests that genetics plays an important role; and it appears that several genes may be responsible for increasing a person's susceptibility to the disease. Most cases of SLE occur sporadically, indicating that both genetic and environmental factors play a role in the development of the disease. Some of the factors that scientists are studying include sunlight, stress, certain drugs, and infectious agents such as viruses. Even though a virus might trigger the disease in susceptible individuals, a person cannot "catch" lupus from someone else.

What Are the Symptoms of Lupus?

Lupus is characterized by periods of illness (flares) and periods of wellness (remission). It is difficult to diagnose because it is often mistaken for other diseases. The following are some common symptoms of lupus:

- Extreme fatigue
- Painful or swollen joints (arthritis)
- Unexplained fever
- "Butterfly" rash across the nose and cheeks that is characteristic to lupus
- Skin rashes on other parts of the body
- Chest pain or pleurisy (inflammation of the pleura, the membrane that covers the lungs)
- Kidney problems
- Unusual loss of hair
- Pale or purple fingers from cold or stress
- Sensitivity to the sun
- Low red blood-cell count
- Seizures
- Mouth or nose ulcers
- Cardiovascular disease

Some people also experience headaches, dizziness, or depression. New symptoms may continue to appear years after the initial diagnosis, and different symptoms can occur at different times.

How Is Lupus Diagnosed?

Early diagnosis and treatment are needed to improve health and reduce tissue damage. Diagnosing lupus can be difficult, however, because it may take months or even years for doctors to piece together the symptoms to make an accurate diagnosis. Giving the doctor a complete, accurate medical history is critical to the process of diagnosis. This information, along with a physical examination and the results of laboratory tests, helps the doctor rule out other diseases that may mimic lupus. Reaching a diagnosis may take time and occur gradually as new symptoms appear.

What Are the Treatments for Lupus?

Because each person's symptoms are different, doctors treat lupus on an individual basis. Once lupus has been diagnosed, the doctor will develop a treatment plan based on the patient's age, gender, health, symptoms, and lifestyle. Tailored to the individual's needs, this plan may change over time. In developing a treatment plan, the doctor has several goals: to prevent flares, to effectively treat them when they do occur, and to minimize complications. The doctor and patient should reevaluate the plan regularly to ensure that it is as effective as possible.

Treatment for lupus includes physical and emotional rest, protection from direct sunlight, a healthful diet, exercise, prompt treatment of infections, avoidance of known allergens and aggravating factors, and medication when necessary. The medication the doctor chooses is based on the patient's individual symptoms and needs. For people with joint pain, fever, and swelling, drugs that decrease inflammation nonsteroidal anti-inflammatory drugs (NSAIDs) are often used. Antimalarials are another type of drug commonly used to treat lupus. They may be used alone or in combination with other drugs to treat fatigue, joint pain, skin rashes, and inflammation of the lungs. Corticosteroid hormones are the mainstay of lupus treatment. Related to cortisol, which is a natural anti-inflammatory hormone, corticosteroids work by rapidly suppressing inflammation. Because they are potent drugs, the doctor will seek the lowest dose with the greatest benefit.

Working closely with the doctor helps ensure that treatments for lupus are as successful as possible. Because some treatments may cause harmful side effects, it is important to promptly report any new symptoms to the doctor.

It is also important not to stop or change treatments without talking to the doctor first. With early diagnosis and the correct treatment and medication, most people with lupus can maintain an overall high quality of life.

SOURCES: National Institute of Arthritis and Musculoskeletal and Skin Diseases, NIH Publication No. 93-3219; Lupus Foundation of America.

Department of Health and Human Services Activities on Lupus

Office on Women's Health (OWH) within the Department of Health and Human Services (DHHS) is the Federal government's focal point for women's health issues. OWH works to improve women's health by coordinating women's health research, health care services, policy, and public and health care professional education across the agencies of the DHHS; and collaborating with other government organizations, and consumer and health care professional groups.

Phone: (202) 690-7650;

Web: <http://www.4woman.gov/owh/about/index.htm>

National Women's Health Information Center (NWHIC), a service of OWH, is a national resource for information on women's health. Through NWHIC, the public and health professionals can access the vast array of Federal and other sources of women's health information.

Phone: 1-800-994-WOMAN (1-800-994-9662);

Web: <http://www.4woman.gov/>

National Institutes of Health (NIH) is the Federal focal point for biomedical research in the United States. The goal of NIH is to acquire new knowledge to help prevent, detect, diagnose, and treat disease and disability. Within NIH, the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) and the National Institute of Nursing Research (NINR) conduct and support research on lupus.

Phone: (301) 496-4000;

E-mail: niinfo@od.nih.gov;

Web: <http://www.nih.gov/>

NIAMS of the NIH leads the Federal medical research effort in arthritis and musculoskeletal and skin diseases. NIAMS supports research and research training throughout the United States as well as on the NIH campus in Bethesda, MD. The National Arthritis and Musculoskeletal and Skin Diseases Information Clearinghouse (NAMSIC) is a public service sponsored by NIAMS that provides health information.

Phone: (301) 495-4484; TTY: (301) 565-2966;

Web: www.nih.gov/niams/

NIAMS has recently produced a manual entitled LUPUS: A Patient Care Guide for Nurses and Other Health Professionals to help health professionals who work with lupus patients to improve their care and quality of life. The guide covers symptoms and diagnosis, advances in lupus research, lab tests for diagnosis and evaluation, lupus medications, health care interventions for general and system-specific manifestations of lupus, psychosocial aspects, and information resources.

National Institute of Nursing Research (NINR), a component of NIH, supports research and research training in universities, hospitals, research centers, and at NIH in areas related to health promotion and disease prevention, managing the symptoms and disabilities of illness, and improving the environment in which patient care is delivered. Chronic diseases, such as lupus and arthritis, are among the six major areas of emphasis for the Institute.

Phone: (301) 496-0207;

Web: www.nih.gov/ninr/

For Further Information...

Federal Agencies

National Women's Health Information Center

Phone: (800) 994-WOMAN (800) 994-9662

Web: www.4woman.gov/

Office on Women's Health - U.S. Department of Health and Human Services

Office on Women's Health
Department of Health and Human Services
200 Independence Avenue, SW, Rm 730B
Washington, DC 20201
Phone: (202) 690-7650
Fax: (202) 690-7172
Web: www.4woman.gov/owh/about/index.htm

National Institute of Arthritis and Musculoskeletal and Skin Diseases
1 AMS Circle
Bethesda, MD 20892B3675
Phone: (301) 495B4484 TTY: (301) 565-2966
Web: www.nih.gov/niams/

National Institute of Nursing Research
NINR Office of Science Policy and Information
31 Center Drive MSC 2178 Building 31, Room 5B10
Bethesda, MD 20892
Phone: (301) 496B0207
Web: www.nih.gov/ninr/

Non-Federal Organizations

Arthritis Foundation
1330 W. Peachtree Street
Atlanta, GA 30309
Phone: (800) 283B7800
Web: <http://www.arthritis.org/>

Association of Rheumatology Health Professionals,
American College of Rheumatology
1800 Century Place Suite 250
Atlanta, GA 30345-4300
Phone: (404) 633-3777
Web: www.rheumatology.org/

Lupus Foundation of America
1300 Piccard Drive, Suite 200
Rockville, MD 20850
Phone: (301) 670-9292 or (800) 558-0121
Web: www.lupus.org/

SLE Foundation
149 Madison Ave., Suite 205
New York, NY 10016
Phone: (212) 685B4118
Web: www.lupusny.org/

Last Updated September 12, 2000

www.4woman.gov -- 800-994-9662 -- 888-220-5446 (TDD)